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Confidentiality in Mental Health with Deaf Populations Perceptions of the Consumer

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Abstract

Confidentiality issues have drawn concern among clinicians in the field of mental health. In part, managed care, fax machines, electronic records, and the use of the internet have added to the concerns related to the protection of client rights, especially related to confidentiality. The issues of confidentiality have always been a concern for therapists who work with deaf and hard-of-hearing individuals. Due to the close-knit nature of the Deaf community, clinicians who provide psychotherapeutic services have the added burden of protection of confidentiality as it relates to chance encounters, dual role and boundary issues between consumers, and the use of interpreters.

Introduction

This article draws upon a three year study in which 17 deaf and hard-of-hearing individuals were interviewed about their subjective experiences in psychotherapy. Two questions guided the study: which considerations are necessary for effective psychotherapy with deaf and hard-of-hearing individuals, and are there specific techniques or processes that are culturally syntonic in psychotherapy with deaf or hard-of-hearing individuals?

A pilot study was conducted in which seven individuals, who were deaf or hard of hearing, faculty and students at Gallaudet University and community members, were interviewed. Upon revision of the methodology, ten additional participants were interviewed. All participants who were part of the actual study were college students at Gallaudet University. This is a significant factor because Gallaudet University is the only liberal arts university for deaf individuals. The unique campus/community emphasizes the practice of sign language as a primary form of communication. Variation in the degree of hearing loss, communication styles, and meaning of deafness among the participants were noted. Table 1 summarizes the demographic characteristics of the population.

Table 1. Demographic Information

	Characteristic	Responses
Self Identification	Deaf	7
	Hard of Hearing	3
Deafness in Family	Parents	1
	Grandparents	2
	Siblings	1
Primary Mode of Communication	ASL	5
	English	2
	Bilingual (oral and manual)	2
	SimCom (voice and sign)	1
School Settings*	Mainstream	8
	School for the Deaf	8
	Deaf class in public school	5
	Private school for hearing child	1
	Public school – no assistance	1

* Adds up to more than 10 because some participants had multiple answers

Each participant answered a demographic questionnaire. The investigator conducted one semi-structured interview with each individual participant. A grounded theory approach was used to analyze the interviews of deaf and hard-of-hearing individuals. Interviews were videotaped and transcribed for pertinent topics and themes. Findings included five areas: accessibility of services, the therapeutic relationship, ego syntonic interventions, cultural knowledge and confidentiality. This article will focus on issues of confidentiality. The major theme includes confidentiality as it relates to the deaf community, mutuality and involvement in protection of confidentiality as it relates to record keeping, special concerns related to confidentiality in work with children, and dual role conflicts encountered in the community.

Stigma of Mental Health

It is important to recognize the stigma of receiving mental health services in the deaf community. Historically, deaf individuals were labeled "deaf/mute or mentally retarded" due to insurmountable communication problems. It is common for deaf individuals to be stereotyped as having deficits in abstract thinking and cognitive abilities (Henwood & Pope, 1994).

The dynamics of mistreatment in the field of mental health are complex. As Falicov (1995) notes, issues of marginalization are integrally associated with language barriers. Inaccessible mental health services have been insurmountable problem for deaf individuals. For example Vernon (1995) observes that most deaf individuals in psychiatric hospitals received only custodial care due to communication barriers. As Steinberg, Loew and Sullivan (1999) point out:

> This need for sensitivity to the values and attitudes of deaf consumers is particularly crucial for those providing mental health services to the deaf population, a minority that is traditionally underserved and seriously over-represented in the populations of correction institutions and mental health inpatient facilities (p. 23).

This long history of misunderstanding and mistreatment has resulted in "a common image of the mental health facility in the Deaf community- it is a place to be feared, a place where people are taken and abandoned, a place where hapless, unsuspecting deaf person might be misunderstood" (Steinberg, Loew, & Sullivan, 1999, p. 32). Although this statement may appear extreme, the continual problems related to stereotyping, inaccessibility and cultural misunderstandings have added to the negative stigma of receiving mental health services. In fact, during the early 1980's as a young social worker in the field of deafness the author spent one year identifying young deaf individuals who were inappropriately placed in mental retardation institutions. Although work was never completed, over 15 young deaf individuals were misplaced in institutions that were inappropriate to their mental health needs.

The stigma of mental health is closely related to the medical rehabilitative paradigm of the need to be "fixed". Although there has been a shift from this paradigm to a model of empowerment informants continue to encounter incidences in which they feel "scapegoated". Several informants of the research project resented that they are

"labeled" as the problem in the family. Sally, an informant, recalls her experience as a young child,

> Well, yes (I felt like I was the problem) with my parents at home. They were the ones who told (the school administrators) that I needed to see a therapist. I think they didn't know how to deal with me because I am deaf and they are hearing.

Perhaps this stigmatization is more strongly experienced in schools for the deaf where privacy is difficult to obtain. Rudy, an informant of this research project stated he would look both ways before entering the school psychologist's office. When asked how he felt about receiving therapy, he described his experience; "Anxious, nervous, concerned about how people perceive me going for therapy, how my family perceived my need for therapy, confidentiality issues". Margery, who, saw her school therapist several times a week during her elementary school years, felt the stigmatization:

> I just felt that I was the only one out of my friends who had to go to therapy. My friends didn't have to go. When I was in the 2nd grade, every Friday during recess time, I had to go to therapy and that bothered me. I had to miss the fun and I always wondered why it was just me and not them. I felt like there was something wrong with me. That made me feel defensive and say that "I was just fine."

The Deaf Community

Individuals who consider themselves part of Deaf culture have several common characteristics that are central to membership in Deaf culture: the loss of hearing, political and personal involvement in the deaf community, the use of ASL and social participation (Lane, Hoffmeister & Bahan, 1996). This social identification is a crucial aspect of deaf culture. Parallel to a small rural community, the Deaf community is close-knit family. Deaf individuals share social, religious, recreational, professional experiences and as previously mentioned school experiences. It is not uncommon to frequently see one another in several social, professional or cultural situations. Deaf people frequently rely on others for news of local events and local happenings through what is commonly called "the deaf grapevine". The nature of the "deaf

grapevine" stirs up concerns about confidentiality. One informant in the pilot study reported that her position in the deaf community was very visible. In order to maintain her anonymity she waited three years to obtain therapy. Another informant, Paula, described the small town nature of the deaf community:

> It might be hard for the deaf therapist to keep information confidential because deaf people are used to sharing information with each other. Or at a deaf party, there is a discussion going on about "that" and the therapist accidentally shares information she got from therapy

Due to the small town nature of the deaf community, clients may encounter each other in waiting rooms within the mental health setting, they may be assigned therapists or interpreters who they know, or clients may encounter their therapist outside the clinical setting.

The Clinical Setting: Preparation for the "Encounter"

One of the fundamental characteristics of the therapeutic relationship is the comfort of the contextual environment of the office setting. As a deaf therapist working in an agency that provided mental health services for deaf individuals in a large cosmopolitan city, situations would occur in which clients, who were intimately involved with each other, would encounter one another in the waiting room. In the waiting room of a mental health agency one very distraught client tearfully recalled her encounter with the current girlfriend of her separated husband. The author established a private practice in a hearing center approximately one hour from any metropolitan city. Many clients traveled over an hour to attend therapy in order to avoid uncomfortable encounters that are common in the deaf community. Although there is not a "set procedure" to deal with chance encounters, the skilled clinician will prepare the client for such encounters and take precautions when necessary. Dorothy, an informant of the research project, discussed the sensitivity of her therapist to the issues of confidentiality in the deaf community. She noted, "We would wait in the waiting room, but after our session, I would leave through another door so her next client would not see me." Preparation for chance encounters between therapist and client appears to be a crucial component of the process:

> She (therapist) did discuss this possibility (meeting her in public places) in our sessions... Also, when I would see her

> in other public places, we would act as if we don't work together (we don't "bump into each other"). She would wait for me to make the first move before talking with me – when I say "hi", she then would respond.

Multiple Relationships

The National Association of Social Worker's Code of Ethics (as cited in Congress, 1996) includes a paragraph pertaining to conflict of interest:

> Social workers should not engage in dual or multiple relationships with clients or former clients in which there is a risk of exploitation or potential harm to the client. In instances when dual or multiple relationships are unavoidable, social workers should take steps to protect clients and are responsible for setting clear, appropriate, and culturally sensitive boundaries. Dual or multiple relationships occur when social workers relate to clients in more than one relationship, whether professional, social, or business. Dual or multiple relationships can occur simultaneously or consecutively (p. 161).

The issue of multiple relationships is a concern in the small-knit Deaf community where it is commonplace for interpreters and professionals to be affiliated with clients in a number of different capacities. Deaf individuals frequently encounter each other in educational, professional, occupational and religious settings, interacting in a number of capacities. Approximately one quarter of the participants of this study noted the difficulty in finding a culturally competent signing therapist. As a last resort, they decided to seek treatment with their friends. All of the participants, however, noted that the therapeutic relationship was compromised due to the dual role dilemma.

> I looked around. For the first therapist, I asked a friend and he recommended this therapist. I thought it wouldn't hurt to try, but that didn't work out. My aunt told me about this other therapist. The therapist was a good person, but I didn't see myself improving very much. For the third therapist, I think my parents told me about him through friends' "word of mouth". As for the fourth one, my friend... he was

> starting to learn how to sign to communicate with people who had special problems. And that was my friend... he was the best one because he knew how to sign. But it was a conflict because he was also a friend and a therapist... but it was not a good idea to have your friend also your therapist.

The issue of inaccessibility contributed to the development of multiple relationships for several of the informants. However all informants noted the problems that occurred. Margaret stated that because there were no signing therapists in the city, she decided to seek help from a friend. She expatiated on the dilemma of confidentiality:

> The confidentiality issue at that time was a big one for me because he was not only my therapist, but he was also my friend... We would see each other at a lot of professional and non-professional events. We belonged to the same Church... The difficulty with that was we had to remember what it was that we discussed in therapy and what we discussed outside of therapy. It was an issue, and that is basically the reason why I stopped therapy with him.

In 1993, the NASW Delegate Assembly voted against dual relationships. However social workers who worked in rural areas reported that dual relationships were unavoidable. Gutman (2002) noted:

> In small communities, however, people may routinely and unavoidably interact with each other in a variety of roles, constituting what some authors prefer to call "overlapping relationships. These overlapping relationships are defined as "unavoidable dual relationships... (resulting) from socio-demographic proximity" (p. 2424).

Although multiple relationships in the Deaf community may be unavoidable, it is the responsibility of the clinician to assess the risks of the dual relationship, avoiding any exploitation or boundary violation. Gutman (2002) notes:

> Ebert (1997) also recognizes the inevitability of certain dual or multiple relationships. He suggests that the mental health

> service (e.g., psychotherapy) be considered the "primary relationship," and that the nature of the proposed "secondary relationship" determined whether a dual relationship is harmful or unethical, or possibly even helpful to the client (p. 2525)

Several considerations that relate to contact with the client may include the frequency of contact, the possibility that the "overlapping relationship" may be avoided, evaluation of other options as well as, consultation related to the consequences of such a relationship. Although there may be incidences when dual relationships can be avoided, there are situations that may present a conflict of interest to both parties. For example, a therapist may have a leadership role in the community that necessitates interaction with a number of people. Most importantly, assessment needs to include any elements of the process that would cause harm or involve boundary violations. It may be important, not only to prepare the client for the possibility of "overlapping roles', but to include the client in a discussion to make joint decisions related to the feasibility of the professional relationship. Finally, Congress (1996) sums up the crucial elements of the dual dilemma:

> When dual relationships develop with former clients, the professional social worker has the responsibility to continually examine the potential harm and exploitation of the client because of the non-therapeutic relationship. The power differential in therapy relationships increases the possibility of exploitation and potential harm to the client in a social relationship (113).

The author's professional experience as a young deaf social worker in a multidisciplinary social service agency supports the numerous relationships that may occur. Later, there were a multitude of encounters when the author entered a deaf academic setting. Current colleagues, students, and supervisees were former clients. Although prior preparations for chance encounters are recommended, preparation in and of itself may be too simplistic an answer to the complications that dual roles may present. As Ebert (1997) recommends, the clinician must always assess the "risks" of the current relationships. Several of the relationships, especially the relationships with current supervisees "transfers", because of the conflicts entailed with being a clinical supervisor of former clients. Meetings with students who were former

clients were necessary to discuss confidentiality issues and clarify boundary issues with former clients who became students. Although there is no prescribed process in addressing each ethical dilemma or dual role conflict, the challenges of a small community appear to necessitate considerations from a perspective of role fluency rather than a role rigidity.

Interpreters

The blurring of boundaries and the "overlapping relationships" present complex ethical issues when the interpreter works in a mental health setting. Usually interpreters may be perceived as being intimately involved in the Deaf community. Because the Deaf community and the people who know sign language are relatively small, it is not unusual for interpreters and clients to know each other from other social or professional contexts (Taylor, 2002). The following case study illustrates the complexity of such involvements (p. 131):

Clark was referred to a counselor because of an onset of acute depression. He stated he could not function and wanted to run away. Upon requesting a counselor, the following transpired:

C: At first, my principal gave me the name of the school counselor, but I didn't feel comfortable with that because I knew her too well and she knew me really well... So she called a hearing counselor from out of town and he came over every weekend and we talked for about 1-2 hours....and I felt better.

During the interview process it became clear that Clark was not comfortable sharing information with his counselor:

R: Why couldn't you tell her everything as a counselor? Was it related to her or it was just you?

Although it took some exploration, it became evident that Clark did not feel comfortable discussing his problems in the presence of an interpreter who he knew.

C: I felt like I was telling my problems to 2 different people and I also knew the interpreter

I confronted Clark with the dilemma

R: I was wondering if that was blocking your counseling... because you had some discomfort with the interpreter being there....that you did not feel safe to talk about different things.

C: You're right...I never thought about that.

In exploration of the process, I wondered why Clark was not able to discuss the issue with his counselor.

C: Were you able to discuss that at all? About your discomfort with the interpreter.

R: I had no choice... the only concern was the interpreter. I was afraid she would tell someone.

Clark stated he knew all the interpreters that worked in his small town. In some respects he felt "stuck". Unfortunately, Clark did not bring his concern to his counselor.

C: I liked that (having an interpreter) because I could understand her better, but the bad thing was that I felt like I was telling my problems to 2 different people and I also knew the interpreter.

R: How did you know that interpreter?

C: I know everyone in my school.

R: How did you feel about that? That you knew the interpreter....what impact did that have on your counseling?

C: I felt funny the first month telling about my problems, but with time, I didn't care and just told her everything. I felt a little uncomfortable.

Clark's therapist was unaware of these dynamics; more importantly Clark was not totally aware of the reasons for his discomfort until the issue was explored;

R: Could you imagine that you and the therapist were communicating directly with each other and that the interpreter was not there? Would that have been different for you?

C: Probably. Maybe that's the answer.....why I didn't tell her everything.

As Lane, Hoffmeister & Bahan (1996) report, "Many deaf clients are reticent in the presence of an interpreter, whom they frequently know and whose discretion they frequently do not trust entirely" (p. 352). The findings of this research supports the contention (Chow & Saldov, 1992) that it may take longer to develop comfort and trust in the therapeutic relationship because of the complexity of two individuals (therapist and interpreter). On the other hand, the clinician must be acutely aware of the combination of feelings, issues and alliances that may develop. Harvey (1989) notes the importance of the numerous roles and alliances that can occur within the treatment setting. For example, contrary to the above example, the presence of an interpreter may symbolize the bridge between two cultural worlds and in fact facilitate the establishment of a rapport. Clients who seek mental health services may not feel comfortable or develop the assertiveness to bring up dilemmas or they may have passively accepted "limitations" related to their deafness. The clinician should take extra precautions in clarifying relationship's prior to the therapy process, directing asking the client if he/she knows the interpreter. Pre-sessions between client and interpreter and interpreter and therapist, may in fact help assess communication styles as well as develop a comfort level. Therefore, it is important for the clinician to understand the clinical dynamics of the diverse triads as well as understanding the symbolic meaning of the presence of an interpreter.

Confidentiality Issues with Children

NASW Code of Ethics addresses the issues of confidentiality (as cited in Congress, 1996):

> Social workers should inform clients, to the extent possible, about the disclosure of confidential information and the potential consequences, when feasible before the disclosure is made. This applies where social workers disclose confidential information on the basis of a legal requirement or client consent (p. 162).

Boundary setting is an important aspect of the treatment process. Children who attend schools for the deaf may feel that the school (family) knows everything about them. They may in fact be more sensitive to issue of confidentiality. Although parents of children have

the right to know what issues their children are dealing with as well as the progress of treatment, several participants of this study expressed concern about the therapist talking with their parents. Lewis, a deaf youngster felt threatened by this process:

> Like I mentioned before, I didn't realize that the psychologist had to share our discussions with my parents. I started seeing a psychologist when I was young, eight or nine years old. Anything I told the psychologist would be reported to my parents...

Lewis discussed the repercussions of the transactions between therapist and his family

> ...caused them to be upset with me and bawl me out for what I discussed in therapy.

This client was struggling with an over-bearing mother. As a consequence of the diffuse boundary issues, Lewis stated;

> ...tired of psychologist telling my parents what I said in sessions...decided to transfer to a private psychologist and felt better after that because nobody, including my mom, knows what was being discussed in therapy.

Although all therapist's need to be aware of the boundaries between families, children and the therapist, Lewis did not understand the parameters of the therapeutic relationship.

> Like I mentioned before, I didn't understand/realize that the psychologist had to share our discussions with my parents. Later on when I changed therapists (when I was 14-15 years old), I realized that there were such things as confidentiality when I didn't understand that before.

Marilyn reiterates the need to teach clients about confidentiality;

> I thought it was interesting that they required us to go (to a school psychologist). They never told us about confidentiality issues and how it worked.

Even when the therapist does explain the parameters related to confidentiality, children may still have anxiety or concern about the process. Jack noted his concern about the process:

> He [therapist] said there was nothing privileged about what I said during therapy because he had the right to discuss it with my mother, because I was very young at that time. But he acted like he didn't share it with my mother. He would ask me to wait in the hallway so he could talk to my mother and that was it. I would have preferred that he told me about it and asked if it was okay to him to share with my mother. I would have preferred him getting my permission first.

Mutuality, the ability of the therapist to involve the client in the process of sharing information was a prevalent theme among several participants. This mutuality, as evidenced by Jack, involves the client in the decision-making process when family members are involved.

Records

Record keeping is a sensitive issue among the participants. Congress (1996) notes, that "many social workers may not be aware that clients have the right to see their own records" (p. 50). She states that social workers are often uncomfortable with this process. Social workers have the responsibility of making sure that the client understands the release form as well as provides the client with a detailed explanation of the process. Several participants of the research study recommended that they be able to not only review the records, but play a role in the process. Lena, emphasizes the importance of mutuality as it related to transfer of her records;

L: My files were transferred to another college. He (therapist) needed to know my background, but I'd like to know what was discussed between them. I don't like it when they discuss things behind my back.

R: You didn't give permission by signing release forms?

L: Yes, I did sign forms, but I wanted them to let me know by getting me involved too

Samuel's discussion reinforces the sensitivity related to record-keeping.

> I thought she was helpful. Everything was fine until she completed the report and I read it. I was disappointed because she wrote down everything in the report...even about my emotions and the negative aspects of it. I didn't know she would include that, but she did. I told her that I wanted some things in the report modified before I approved of it. All she did was laugh at me and tell me that it was fine. I was thinking to myself... "ok, fine, but don't joke about it". I asked to meet with her again after I read through the report and discussed what I wanted changed in the report. She didn't take me seriously, so I was disappointed about that.

This mutual involvement with record keeping and ultimately confidentiality issues is closely associated with empowerment processes. As a result of numerous experiences of oppression, having been told what to do and how to do it for most of their lives, active involvement of the client in the safeguarding of confidentiality is highly recommended. "Protecting the client's interests in both oral and written communications is essential to ethical practice" (Congress, 1996, p. 52).

Implications for Professionals

It is important to reiterate the importance and delicate nature of confidentiality for deaf professionals in the field. Although the Deaf community is small, the professional deaf community-educators, doctors, and researchers is even smaller. Professionals need to take extra precaution when sharing information about clients, not only among the treatment team, but during case conferences, supervision or consultation. Schools for the deaf, deaf social service and mental health agencies, as well as universities need to pay attention to the assignment of clients, the training of interns, and the mechanics of information sharing among team members and students in educational settings. Researchers in the field of deafness must take added precautions to camouflage materials.

The importance of confidentiality may take on greater significance in the deaf community than the hearing community, not only because of the close-knit nature of the community and the stigma involved in receiving mental health services, but the nature of the "grapevine" that acknowledges that adults do talk about children especially in deaf settings such as the school for the deaf or mainstream programs. Although participants were less concerned about hearing therapists who were not involved in the Deaf community, the use of interpreters triggered ethical concerns. Clinicians need to be aware of the complexity of multiple role relationships as it relates to the therapist/clinician/ interpreter triad. Clinicians are responsible to make assessments of the nature of the relationships and risk of client care. Clinicians need to be aware of preparing clients for chance meetings, maintaining an open dialogue in the exploration of possible dual role dilemmas, and maintain some role flexibility in addressing concerns and making decisions that are in the best interest of the client.

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